



Panel 2: Maintaining Momentum with Administrative Data

September 21, 2026

Jennifer Kucera, Moderator

I/DD Counts Summit





What is Administrative Data?

- Information collected by programs or services when people use them. This is sometimes called program data.
- It is NOT collected for research, but it can give good information
- What are we learning from administrative data about the health of people with IDD?



Panelists

- **Jeffrey Galecki**, Centers for Medicare and Medicaid (CMS)
- **Chip Haltermann**, Office of Assistant Secretary for Planning and Evaluation (ASPE)
- **Rhonda Eppelsheimer**, Oregon Health Sciences UCEDD
- **Eric Rubenstein**, Boston University
- **Leanne Candura**, Human Services Research Institute (HSRI)

- Question and Answer

Centers for Medicare and Medicaid

Jeffrey Galecki, MS, LCADC, LCPC
Social Science Research Analyst
I/DD Summit, September 21, 2026

Mission of Centers for Medicare & Medicaid Services

To serve as a trusted partner and steward, dedicated to
advancing health equity,
expanding coverage, and
improving health outcomes for millions of Americans.

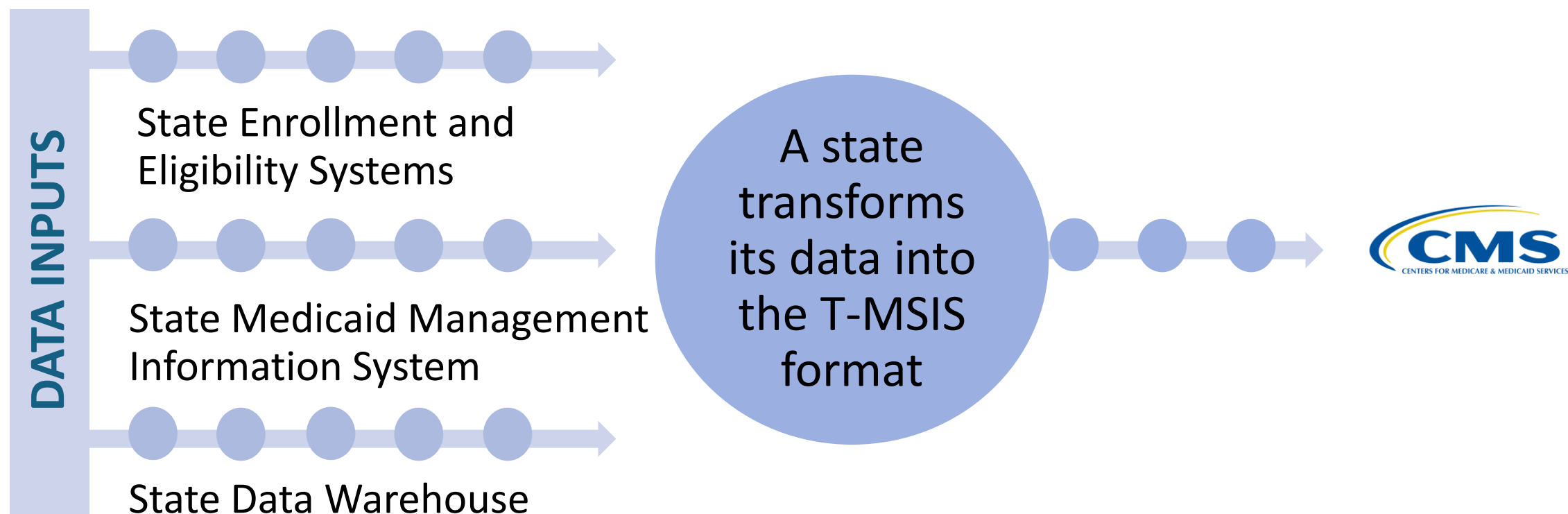
Three Pillars of Coverage

Medicare	Medicaid & CHIP	Health Insurance Marketplace
Health insurance for seniors aged 65+ and younger individuals with specific disabilities.	Joint federal-state programs for low-income families, individuals, and children.	Platform created by the Affordable Care Act for purchasing individual health plans.

Transformed Medicaid Statistical Information System (T-MSIS)

A data system that captures information on all Medicaid and CHIP enrollees, the services they use, and the providers and managed care plans that serve them.

Each state information system is unique



Most states contract with a vendor to pull data from their systems and get it into the T-MSIS format

What is TAF?

Enhanced version of T-MSIS data tailored to research needs of Medicaid and CHIP data users with data covering:

- Beneficiary demographics
- Eligibility
- Program enrollment
- Managed care
- Providers
- Service use
- Payments



TAF data are easier to use for research purposes than T-MSIS data.

TAF's purpose?

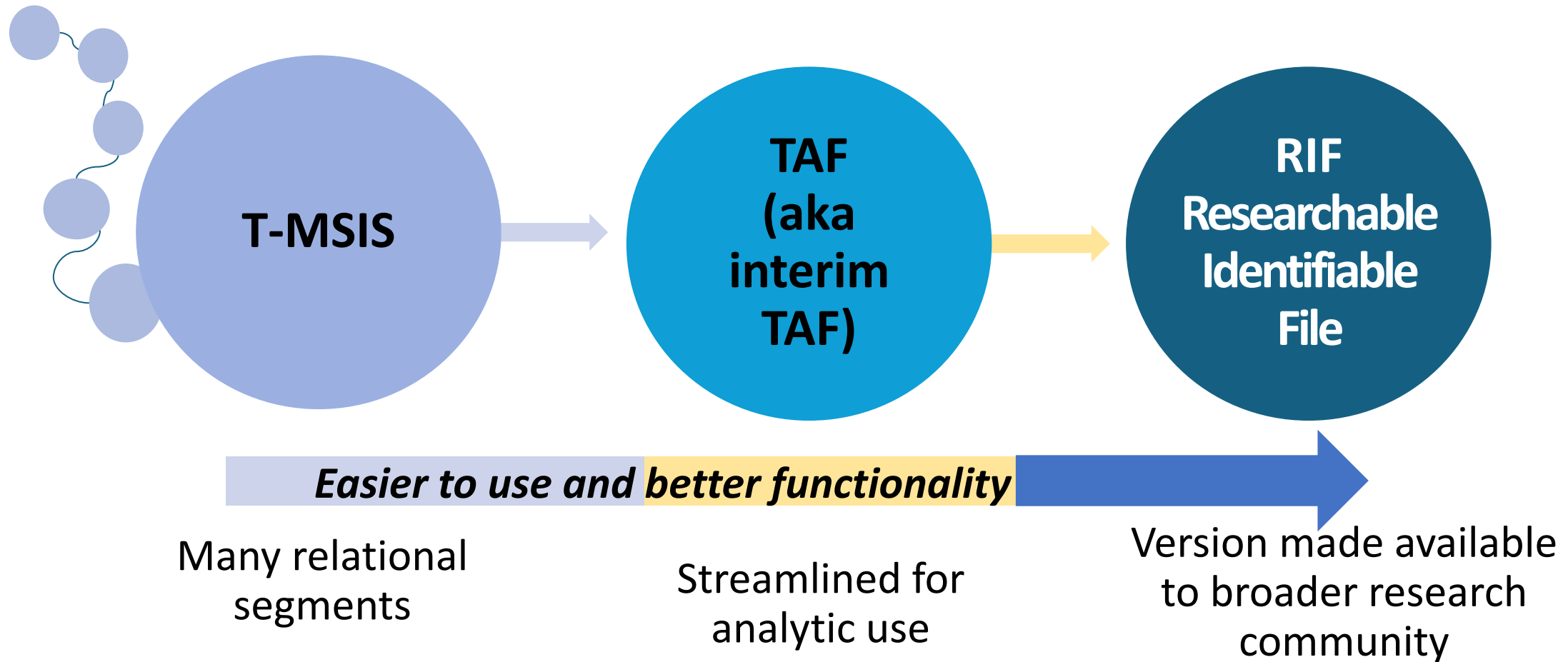
Analyzing T-MSIS data can be a challenge

- **Files are large and complex**
- **Updated every month**

CMS created the TAF to support analysis, research, and data-driven decisions on key dimensions of Medicaid and CHIP:

- Expenditures
- Enrollment patterns
- Program evaluation
- Policy assessment
- Health care quality
- Provider participation

Making the data easier to use



Behavioral Health (BH) Data Book:

- Data is used to build the Behavioral Health (BH) Dashboard
- Congressionally mandated
- Uses Transformed Medicaid Statistical Information System (T-MSIS) Analytic Files (TAF) data to analyze and develop counts
- Currently, BH Data Books are published on the [Medicaid.gov TAF site](#).
 - SUD Data Books from 2017-2021 are also published on the site

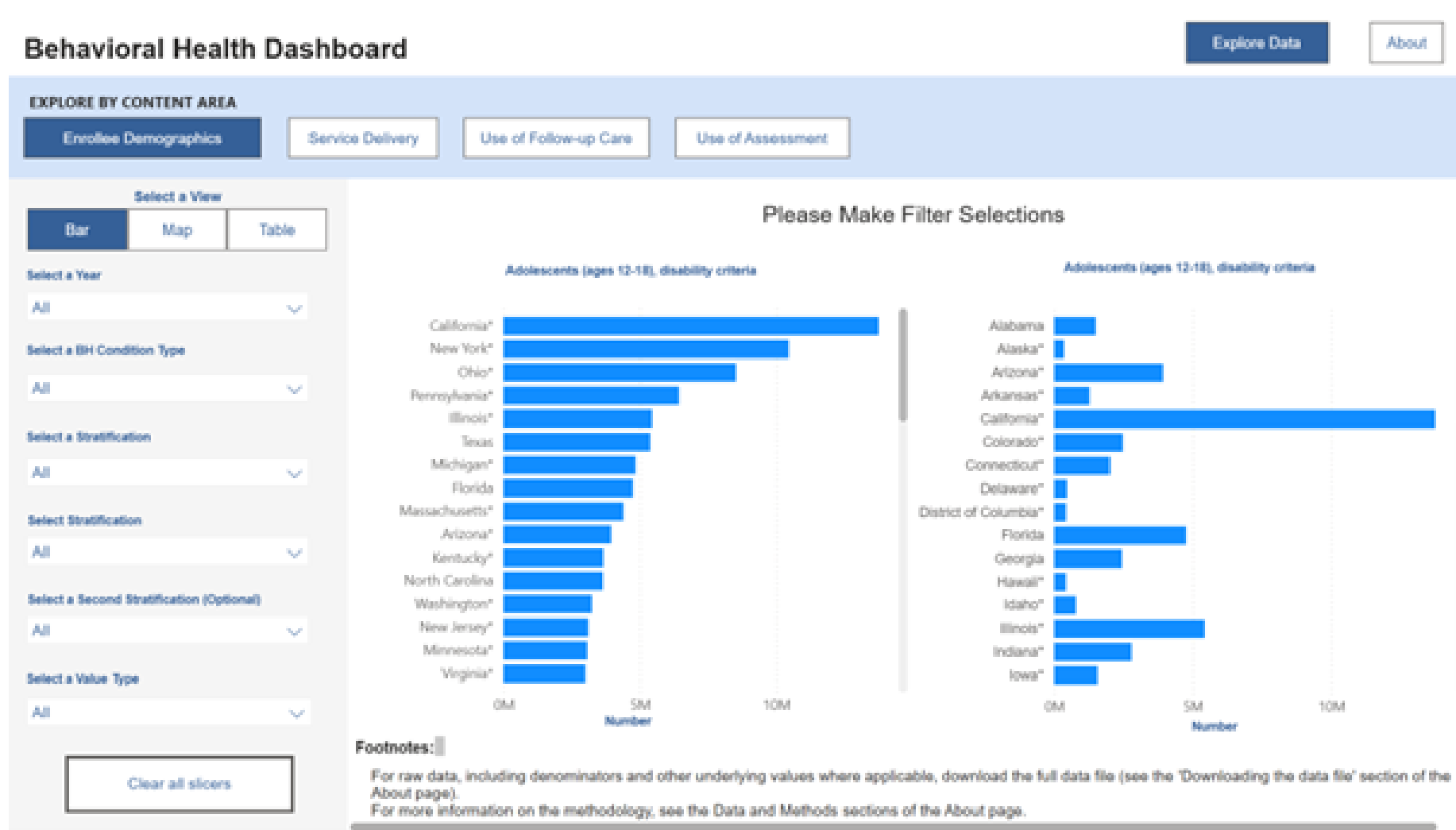
BH Data Book Comprises:

Diagnostic categories are consistent with those in the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition, Text Revision (DSM-V-TR; American Psychiatric Association [APA] 2022).

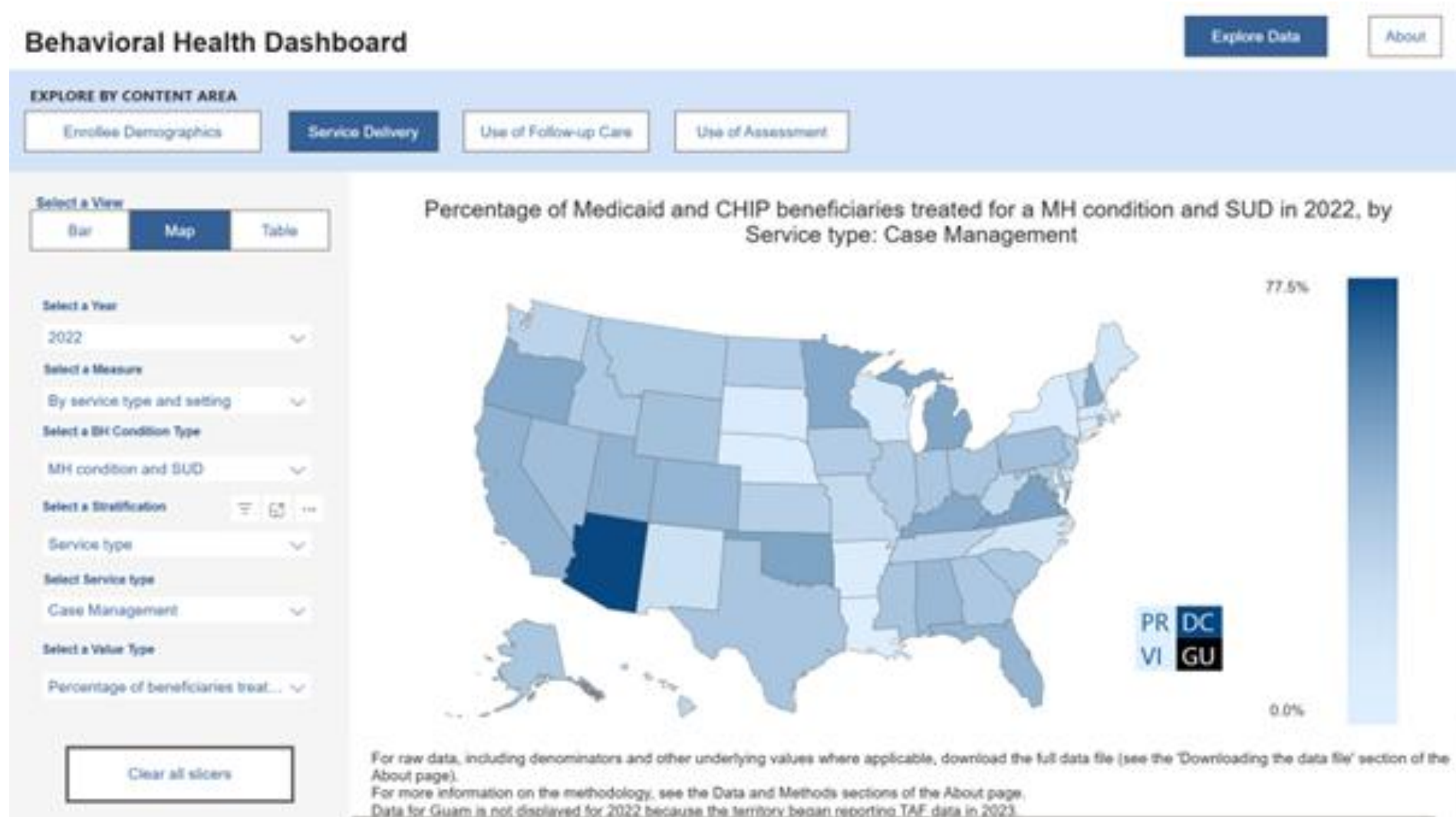
Behavioral Health (BH) Data Book Dashboard

- According to the Section 202 of the Consolidated Appropriations Act, 2024 (P. L. 118-42), the U.S. Department of Health and Human Services is required to publish a revised version that allows for a research-ready and publicly accessible interface no later than three years after the enactment of the law (by 3/9/27).
- CMS has procured business intelligence software (Power BI) to develop a public-facing interactive dashboard to meet the legislative requirement.
 - This dashboard will replace the static Behavioral Health Data Book.
- The Behavioral Health (BH) Dashboard provides interactive visualizations of behavioral health
- The 2022 BH Data Book data is used for this first **test** iteration of the dashboard
 - 2024 BH Data Book data will be available in the first **public** iteration of the dashboard (by 3/9/27)

Example: Bar Graph View, Enrollee Demographics



Example: Map View, Service Delivery



Thank You!

Contact information:
jeffrey.galecki@cms.hhs.gov

2026 I/DD Counts Summit

Putting the Pieces Together: Better Data for People with Intellectual and Developmental Disabilities (I/DD)



Chip Haltermann
Office of the Assistant Secretary for Planning and Evaluation (ASPE)
U.S. Department of Health and Human Services

ASPE helps HHS use research and data to guide policy and improve programs

A 2021 ASPE report identified broad opportunities to improve data used in I/DD research. A 2022 follow-up highlighted three priorities:

1. Record I/DD status consistently

Use common standards in health records.

2. Measure what matters over time

Improve how important outcomes are measured and track changes over time.

3. Link Medicaid data with other data

Connect federal Medicaid data (T-MSIS) with other federal data sources.

[Read 2021 report →](#)

[Read 2022 report →](#)



ASPE
ASSISTANT SECRETARY FOR
PLANNING AND EVALUATION

OFFICE OF BEHAVIORAL HEALTH,
DISABILITY, AND AGING POLICY

Two ASPE projects move this work forward

One project studied who is counted. The other links data to study outcomes.

How studies identify people with I/DD in data→

Studies use different codes and rules to decide who is counted as having I/DD.

Why it matters: Gives researchers a clearer path for identifying people with I/DD in health care data.

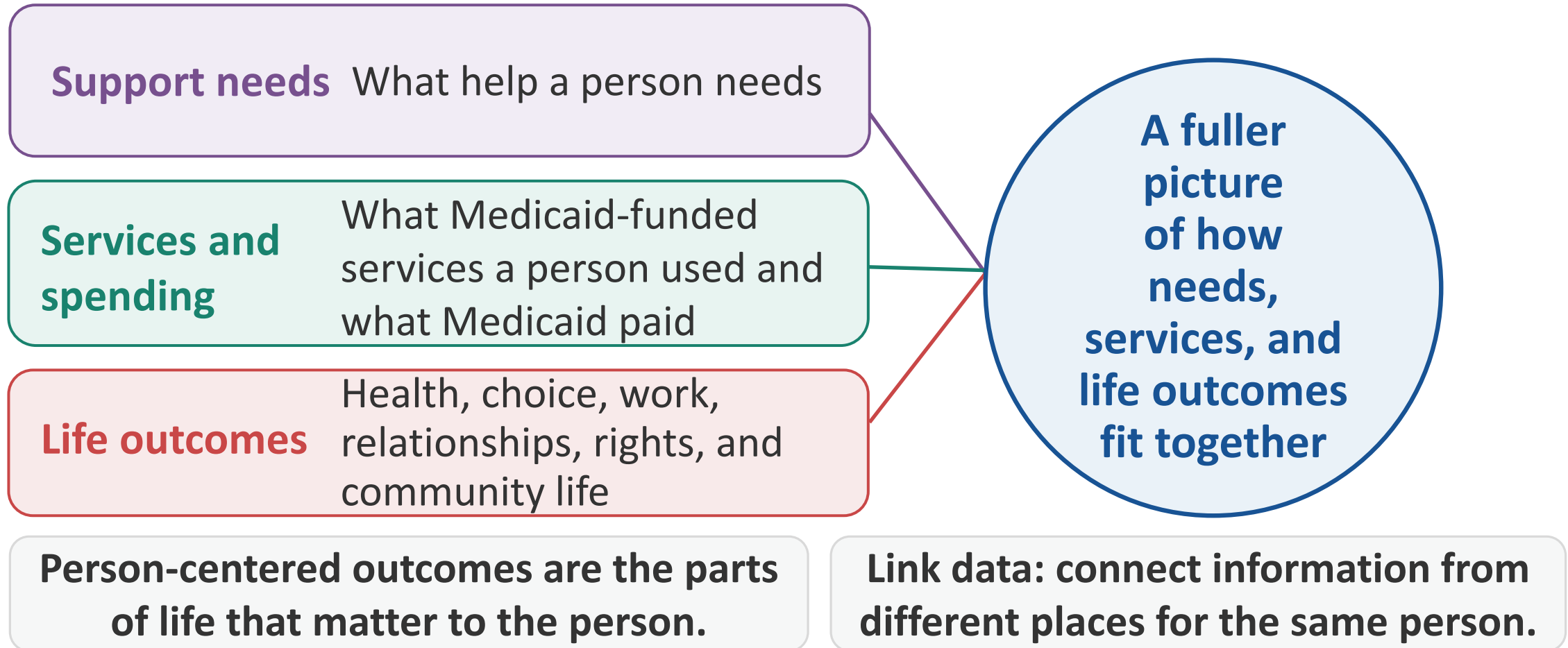
Integrated Dataset on Intellectual and Developmental Disabilities (iDIDD)

Links state data on support needs, services, Medicaid spending, and life outcomes for people with I/DD.

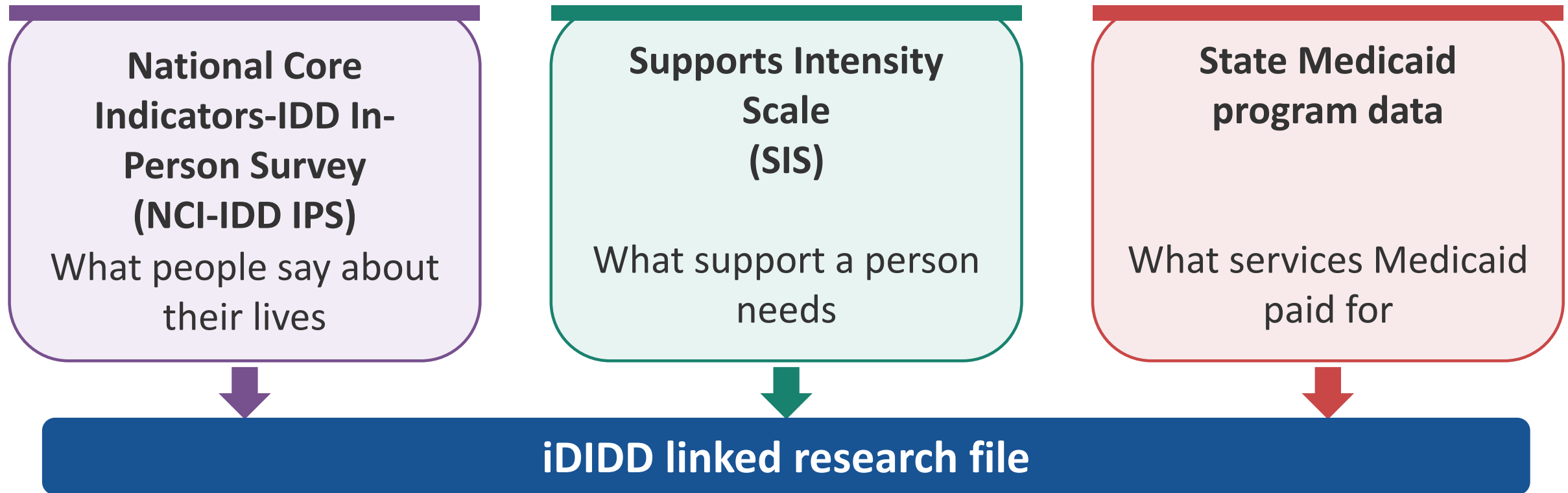
Why it matters: Helps researchers study how needs, services, spending, and life outcomes are related.



Linking data gives a fuller picture



Integrated Dataset on Intellectual and Developmental Disabilities (iDIDD) links three data sources



Data sources and years differ by state. The project uses personally identifiable information to match records, then removes it from the final research file.



iDIDD has four state partners

State	NCI-IDD IPS Years	Medicaid Data Years	SIS Years	People with linked records
Georgia (GA)	2017-2020	2016-2022	2015-2025	About 1,600
Kentucky (KY)	2017-2022	2016-2022	2016-2024	About 1,900
Pennsylvania (PA)	2017-2021	2016-2023	2017-2021	About 2,800
California (CA)	Not yet final	Not yet final	Not included	Not yet final

Years of data and counts of people are preliminary and may change.



Linked data can help answer questions no single source can



iDIDD can guide future data work

1. Build trust and choose a lead

Agree on the goal, explain how privacy will be protected, and choose one person to keep the work moving.

Helps partners stay involved.

2. Start early

Bring in state Medicaid, I/DD services, legal, privacy, and data staff. Plan extra time for approvals.

Helps reduce delays.

3. Plan for state differences

Use a shared file format and clearly document how each state's data differ.

Helps others repeat the work.



Acknowledgements

I/DD Data Infrastructure Report Authors

Rina Dhopeswarkar
Krysta Heaney-Huls
Lauren Hovey
Desirae Leaphart
Prashila Dullabh

I/DD Data Infrastructure Report Authors

Christina Rotondo
Frances Jiménez
Sofia Ryan
Emma Plourde
Madjid Karimi

Claims Definition Report Authors

Anna Sommers
Giuseppina Chiri
Nicholas Rios
Michael Hayes
Emma Plourde
Madjid Karimi
Amanda Reichard



Acknowledgements (continued)

iDIDD Project Team

Emma Plourde
Bill Marton
Pamela Doty
Helen Lamont
Benjamin Allaire
Giuseppina Chiri
Olga Khavjou

iDIDD Project Team

Jennifer Howard
Matthew Walton
Adele Namboodri
Claire Strack
Nicholas Rios
Villacorta
Parthenia Dinora

Special Thanks

- State partners
- Technical expert panel members
- Stakeholder meeting attendees



Contact

Chip Haltermann

william.haltermann@hhs.gov



ASPE
ASSISTANT SECRETARY FOR
PLANNING AND EVALUATION

OFFICE OF BEHAVIORAL HEALTH,
DISABILITY, AND AGING POLICY



Closing the Gap

What Medicaid Data Can Tell Us About the Health of Adults with Intellectual and Developmental Disabilities (I/DD)

Date: September 2026

Presented by: Rhonda Eppelsheimer, MSW/LCSW
OHSU UCEDD Director

Important Information

Presenter

No financial benefit from this presentation.

Project Funding

- Administration for Community Living (ACL), #90UCPH0061-01-01
- Oregon Council on Developmental Disabilities, #178396 (ACL funds)

What We Will Talk About Today

- Why states need better data about the health of people with I/DD.
- Share how people with I/DD can be partners in data projects.
- Learn ways to share data with the community using easy-to-understand reports and a data dashboard.

Why Better State Data Matters

- Helps state leaders and public health programs better understand and respond to people's needs.
- Helps states make better policy and program decisions.
- Helps us understand people's health, healthcare, and barriers to care.
- Working with people with I/DD helps make sure the data reflects their experiences and what matters to them.

What Did We Do

- 1) Analyzed Medicaid Health Data
- 2) Developed a Report with Recommendations
- 3) Developed an Interactive Public Data Dashboard
- 4) Developed Accessible Reports on What We Learned

Working Together with Partners

- People with I/DD and community partners
- Disability advocacy organizations
- State health and disability partners
- Researchers and data experts
- Healthcare and training partners

What Did We Decide to Study

We looked at six areas of health

- Mental Health Care
- Substance Use (like alcohol and drug usage)
- Hospital Stays and Emergency Department Visits
- Diabetes
- Dental Care
- Cancer Screenings

How We Looked at the Data

- Used 2022 Oregon Medicaid data
- Identified adults with and without I/DD
- Created similar groups for comparison
- Looked at differences across groups
- Improved race and ethnicity information
- Used clear rules to protect data quality and privacy

What This Data Cannot Tell Us

- Some people with I/DD may be missing
- Only includes Medicaid data from 2022
- Shows one point in time
- Some groups were too small to compare

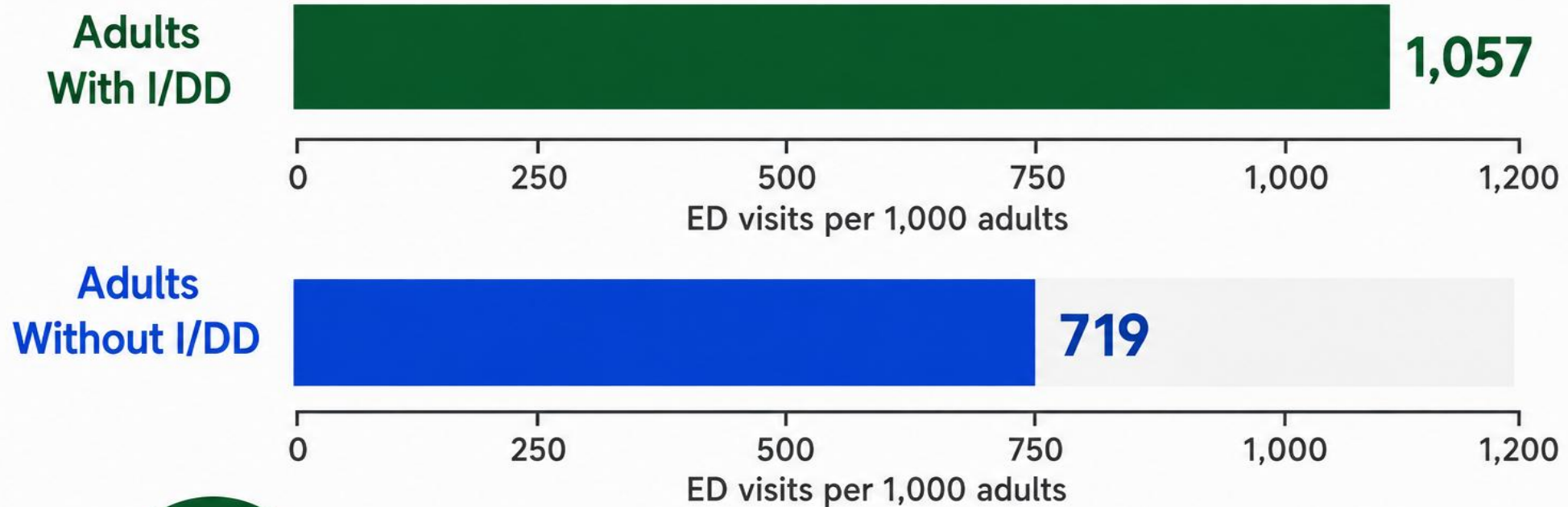
A Few of the Key Findings

Compared with adults without I/DD, adults with I/DD had:

- More emergency department visits
- Lower rates of cervical cancer screening
- More hospital readmissions within 30 days

Emergency Department (ED) Visits much higher for Medicaid members with I/DD

Number of ED Visits per 1,000 Adults in 2022



1.5x

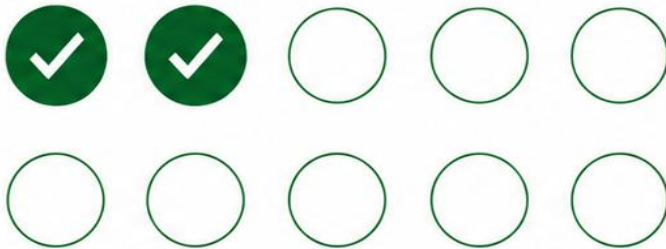
Medicaid adults with I/DD had about **1.5 times as much** ED visits per 1,000 adults **than** adults without I/DD.

Medicaid Members with I/DD were less likely to receive cervical cancer screenings compared to those without I/DD

Percent of Adults Who Received Cervical Cancer Screening

With I/DD

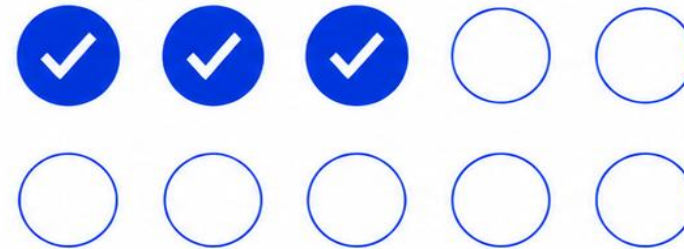
21.7%



About 2 out of 10
adults screened

Without I/DD

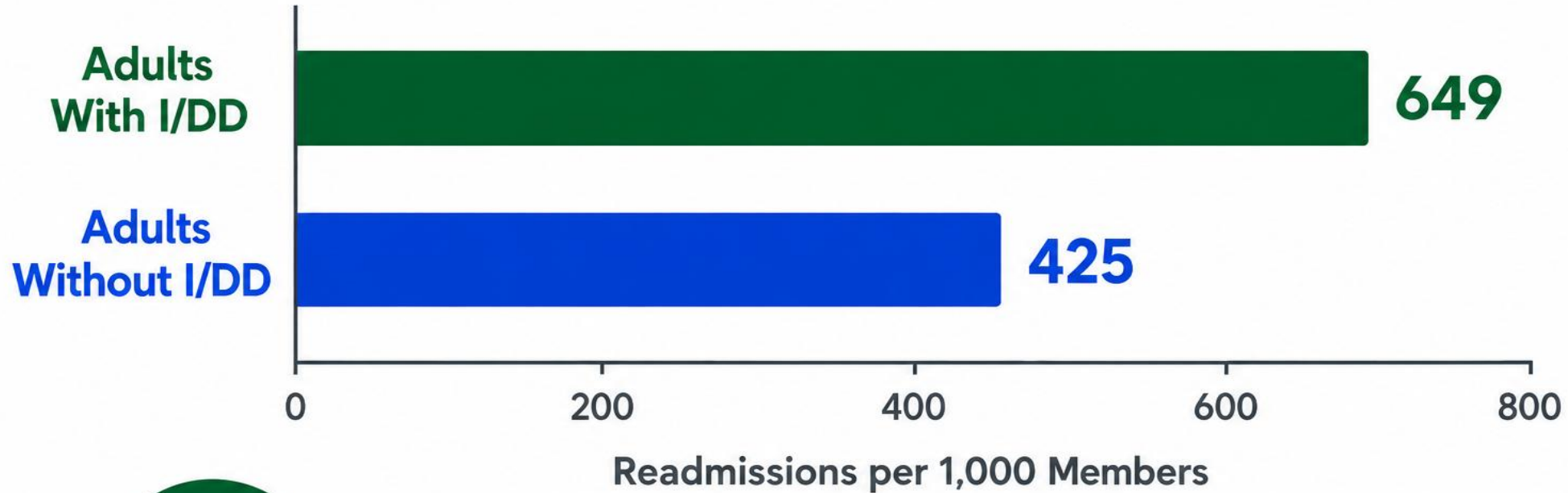
27.1%



About 3 out of 10
adults screened

30-day All-Cause Readmissions much higher for Medicaid members with I/DD

Number of 30-day All-Cause Readmissions per 1,000 Members



1.5x

Medicaid members with I/DD had about **1.5 times as much** readmissions per 1,000 members **than** members without I/DD.

What We Learned-What's Next

- Build the data
- Look beyond the comparison
- Ask deeper questions
- Center lived experience
- Share, partner, and act



Thank You

Rhonda Eppelsheimer- UCEDD Director

eppelshe@ohsu.edu

www.ohsu.edu/ucedd

Medicaid and Medicare data for intellectual disability: better than advertised

Eric Rubenstein, PhD, Boston University

No conflicts

Data history

- First used state Medicaid data in 2017-2020
- Purchased 9 years of Medicaid data in 2021 (years 2011-2019)
- Purchased 2 more in 2024 (years 2023-2024)
- Use physical data files
- Linked to Medicare
- Adults with autism, intellectual disability, and Down syndrome with randomly selected other Medicaid beneficiaries (N=1.6 million with IDD, 5 million total)

What are the big concerns of the data?

- Data quality and completeness
- State differences
- Enrollment eligibility and complexity

1. Data quality and completeness

- The system was not designed for research so there are issues
- Data entry issues
 - Header records without primary procedure code
 - Missing claim type code
- Completeness issues
 - Some states did not report any data for certain files

1. Data quality and completeness

There are great resources for understanding the data limitations

Medicaid.gov
Keeping America Healthy



DQATLAS

Explore the quality and usability
of Medicaid and CHIP data in
T-MSIS Analytic Files (TAF)

HOW TO USE DQ ATLAS

DQ (Data Quality) Atlas includes data quality information that supports insightful, methodologically sound analyses using the T-MSIS Analytic Files (TAF) Research Identifiable Files (RIF). Select one of the below pathways to explore key Medicaid and Children's Health Insurance Program (CHIP) topics such as enrollment, claims, expenditures, and service use.

EXPLORE BY TOPIC

View data quality assessments on topics such as enrollment, claims, expenditures, and

EXPLORE BY STATE

View data quality assessments for a selected state for all available topics.

ANALYTIC BRIEFS

Download additional analyses of T-MSIS data and Research Identifiable Files.

RESOURCES

Learn more about DQ Atlas and how it can support your work.

1. Data quality and completeness

Linking Across FilesTOPICS	Income	FFS Long-Term Care Expenditures	Diagnosis Code - LT	Billing Provider NPI - RX
Linking Claims to Beneficiaries	ZIP Code	FFS Other Medical Expenditures	Diagnosis Code - OT	Servicing Provider NPI - OT
Linking Expenditures to Beneficiaries	Eligibility Group Code	FFS Prescription Drug Expenditures	Procedure Codes - IP	Prescribing Provider NPI - RX
Linking Claims to Providers	Dual Eligibility Code	Total Monthly Beneficiary Payments	Procedure Codes - OT Professional	Dispensing Provider NPI - RX
Linking Beneficiaries to Managed Care Plans	CHIP Code	CMC Payments	Procedure Codes - OT Institutional	Billing Provider Type, Specialty, and Taxonomy - IP
Total Medicaid and CHIP Enrollment	Restricted Benefits Code	PHP Payments	Type of Service - IP	Billing Provider Type, Specialty, and Taxonomy - LT
Medicaid-Only Enrollment	Primary Language	PCCM Fees	Type of Service - LT	Billing Provider Type, Specialty, and Taxonomy - OT Professional
M-CHIP and S-CHIP Enrollment	English Language Proficiency	Premium Assistance Payments	Type of Service - OT	Billing Provider Type, Specialty, and Taxonomy - OT Institutional
Dually Enrolled in Medicare	American Indian and Alaska Native Indicator	Missing Payment Data - FFS Claims	Type of Service - RX	Billing Provider Specialty and Taxonomy - RX
Enrollment in CMC Plans	Claims Volume - IP	Missing Payment Data - Encounters	Place of Service	Servicing Provider Type, Specialty, and Taxonomy - OT Professional
Enrollment in PCCM Programs	Claims Volume - LT	Bundled Payments for Prenatal Care	Admission Date - IP	Servicing Provider Type, Specialty, and Taxonomy - OT Institutional
Enrollment in BHO Plans	Claims Volume - OT	Payment Data Consistency - IP	Admission Date - LT	Hospital Type - IP
Adult Expansion Enrollment	Claims Volume - RX	Payment Data Consistency - LT	Discharge Date - IP	Active Enrollment Status Indicator
Newly Eligible Adult Enrollment	Service Users - IP	Payment Data Consistency - OT	Discharge Date - LT	Facility/Group/Individual Code
1915(c) Participation	Service Users - OT	Payment Data Consistency - RX	Type of Bill - IP	Group and Individual Providers - Classification Types
SSI Participation	Service Users - RX	Category of Service Code - IP	Type of Bill - LT	Facilities - Classification Types
1115 Demonstration Identification	Availability of CMC Plan Encounter Data	Category of Service Code - LT	Type of Bill - OT	Facility Characteristics
Number of Enrollment Spans	CMC Plan Encounters - IP	Category of Service Code - OT	Generic Indicator - RX	Provider Location
Length of Enrollment Gaps	CMC Plan Encounters - LT	Category of Service Code - RX	National Drug Code - RX	National Provider Identifier
Overlapping Enrollment Spans	CMC Plan Encounters - OT	Federal Reimbursement Category Code - IP	Days' Supply, Quantity, and Units - RX	Managed Care Plan Program and Population Characteristics
Age	CMC Plan Encounters - RX	Federal Reimbursement Category Code - LT	Supplemental Payments	Managed Care Plan Operational Characteristics
Sex	Benchmarking Inpatient Stays - IP	Federal Reimbursement Category Code - OT	Non-Program (Other) Claims	Plan Name and Type
Race and Ethnicity	Total Medicaid Expenditures	Federal Reimbursement Category Code - RX	Service Tracking Claims	Claims Volume - IP
CMC Plan Encounters - IP	Medicaid Beneficiary Expenditures	Diagnosis Code - IP	Billing Provider NPI - IP	Service Users - IP
Benchmarking Inpatient Stays - IP	Total FFS Expenditures	FFS Prescription Drug Expenditures	Billing Provider NPI - LT	
FFS Inpatient Expenditures	FFS Inpatient Expenditures	Payment Data Consistency - RX	Billing Provider NPI - OT	
Payment Data Consistency - IP	Claims Volume - OT	Category of Service Code - RX	Billing Provider NPI - RX	
Category of Service Code - IP	Service Users - OT	Federal Reimbursement Category Code - RX	Servicing Provider NPI - OT	
Federal Reimbursement Category Code - IP	CMC Plan Encounters - OT	Type of Service - RX	Prescribing Provider NPI - RX	
Diagnosis Code - IP	Total Monthly Beneficiary Payments	Generic Indicator - RX	Dispensing Provider NPI - RX	
Procedure Codes - IP	CMC Payments	National Drug Code - RX	Billing Provider Type, Specialty, and Taxonomy - IP	
Type of Service - IP	PHP Payments	Days' Supply, Quantity, and Units - RX	Billing Provider Type, Specialty, and Taxonomy - LT	
Admission Date - IP	PCCM Fees	Billing Provider NPI - RX	Billing Provider Type, Specialty, and Taxonomy - OT Professional	
Discharge Date - IP	Premium Assistance Payments	Prescribing Provider NPI - RX	Billing Provider Type, Specialty, and Taxonomy - OT Institutional	
Type of Bill - IP	Payment Data Consistency - OT	Dispensing Provider NPI - RX	Billing Provider Specialty and Taxonomy - RX	
Billing Provider NPI - IP	Category of Service Code - OT	Billing Provider Specialty and Taxonomy - RX	Servicing Provider Type, Specialty, and Taxonomy - OT Professional	
Billing Provider Type, Specialty, and Taxonomy - IP	Federal Reimbursement Category Code - OT	APR File DQ TopicsTOPICS	Servicing Provider Type, Specialty, and Taxonomy - OT Institutional	
Hospital Type - IP	Diagnosis Code - OT	Linking Claims to Providers	Hospital Type - IP	
Claims Volume - LT	Procedure Codes - OT Professional	Active Enrollment Status Indicator	Active Enrollment Status Indicator	
CMC Plan Encounters - LT	Procedure Codes - OT Institutional	Facility/Group/Individual Code	Facility/Group/Individual Code	
FFS Long-Term Care Expenditures	Type of Service - OT	Group and Individual Providers - Classification Types	Group and Individual Providers - Classification Types	
Payment Data Consistency - LT	Place of Service	Facilities - Classification Types	Facilities - Classification Types	
Category of Service Code - LT	Type of Bill - OT	Facility Characteristics	Facility Characteristics	
Federal Reimbursement Category Code - LT	Billing Provider NPI - OT	Provider Location	Provider Location	
Diagnosis Code - LT	Servicing Provider NPI - OT	National Provider Identifier	National Provider Identifier	
Type of Service - LT	Billing Provider Type, Specialty, and Taxonomy - OT Professional	Linking Beneficiaries to Managed Care Plans	Managed Care Plan Program and Population Characteristics	
Admission Date - LT	Billing Provider Type, Specialty, and Taxonomy - OT Institutional	Managed Care Plan Program and Population Characteristics	Managed Care Plan Operational Characteristics	
Discharge Date - LT	Servicing Provider Type, Specialty, and Taxonomy - OT Professional	Managed Care Plan Operational Characteristics	Plan Name and Type	
Type of Bill - LT	Servicing Provider Type, Specialty, and Taxonomy - OT Institutional	Plan Name and Type	Claims Volume - IP	
Billing Provider NPI - LT	Claims Volume - RX		Service Users - IP	
Billing Provider Type, Specialty, and Taxonomy - LT	Service Users - RX			
	CMC Plan Encounters - RX			

1. Data quality and completeness

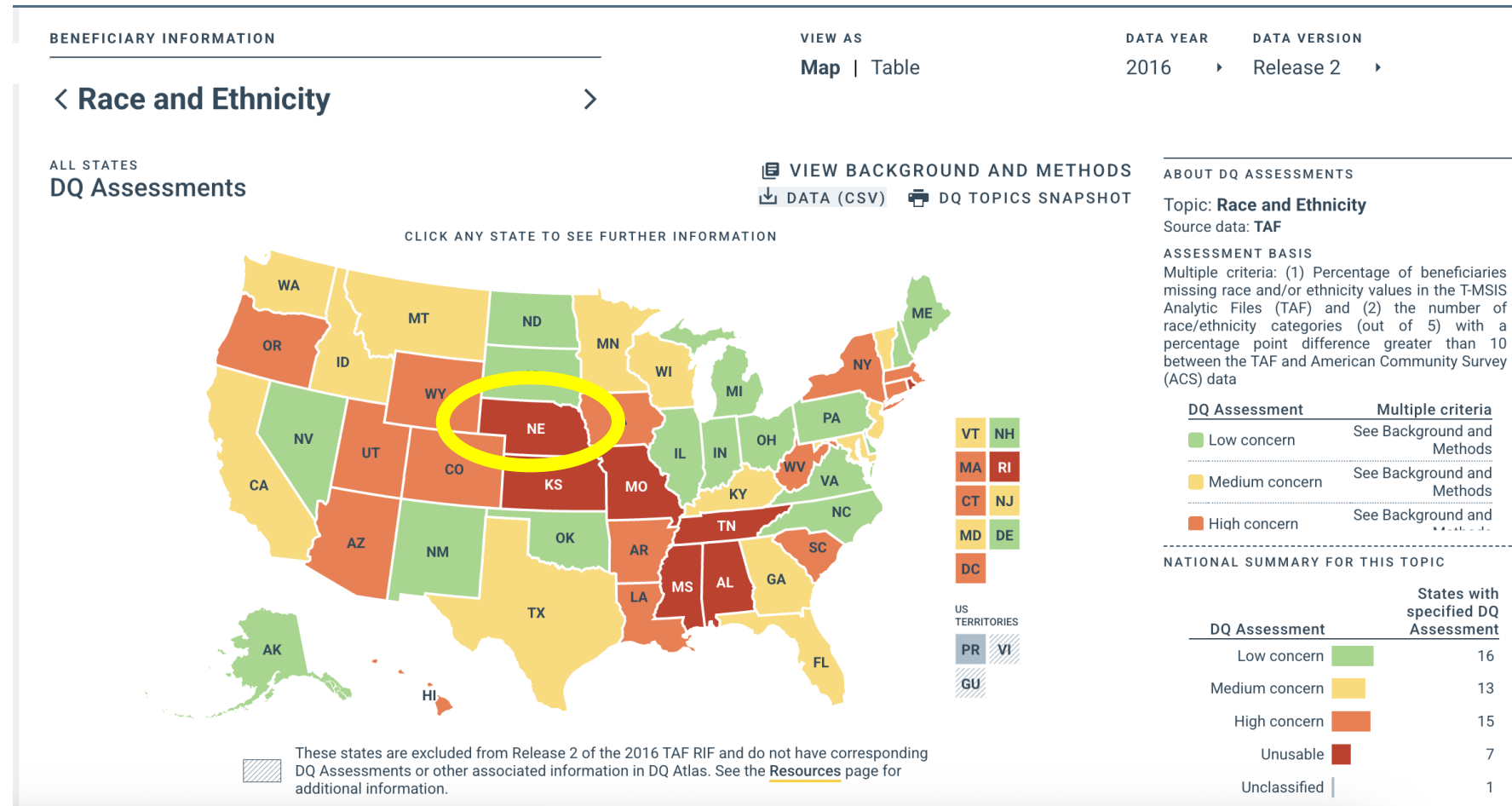
Why am I not as concerned as other TMSIS researchers?

Consistency (no churn **or lack of people enrolling and disenrolling and reenrolling...**) for enrollment for people with IDD overcomes many data gaps (plus potential for linking to Medicare). We have more opportunity for states to report important demographic data.

1. Data quality and completeness

Example:

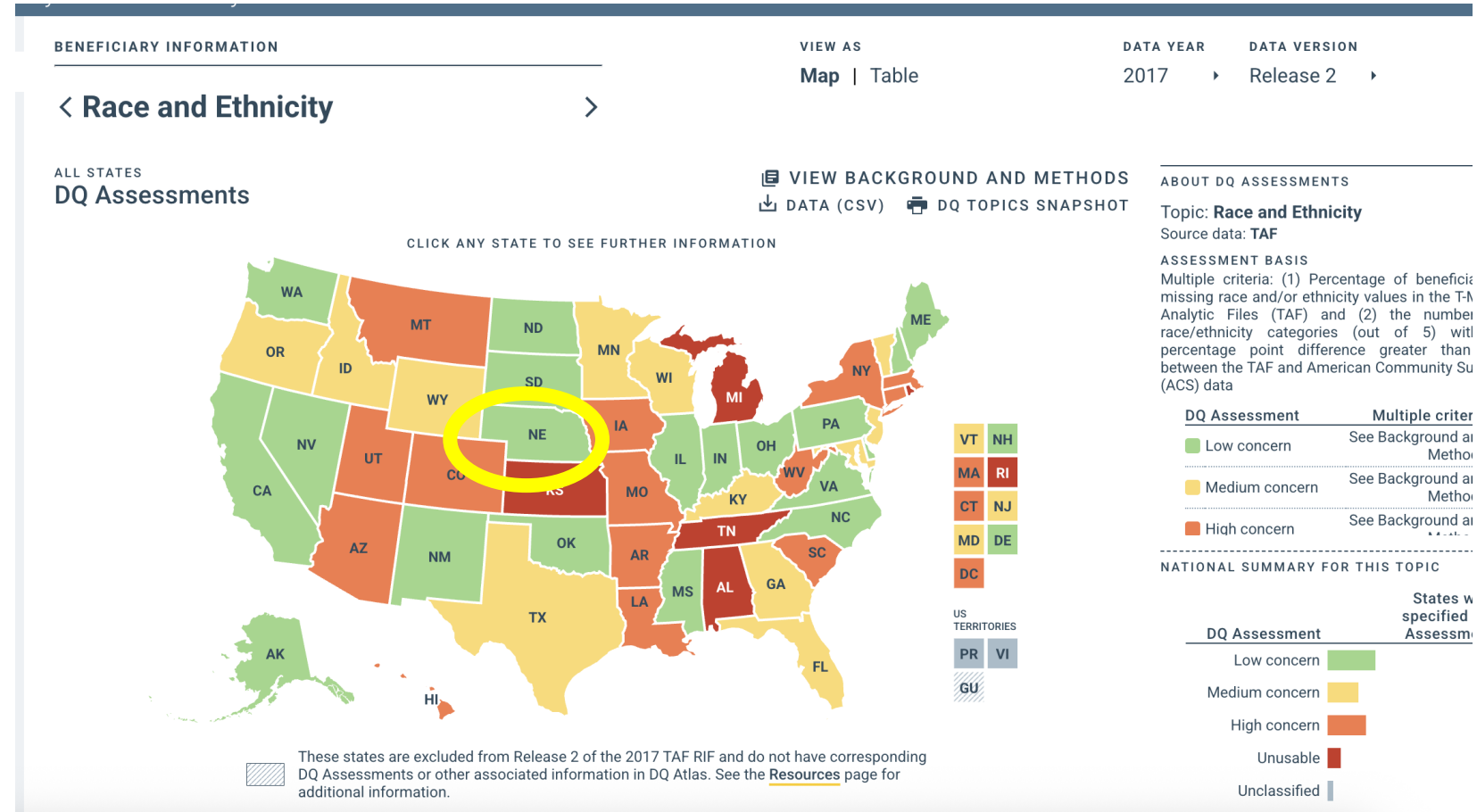
Nebraska is unusable for race in 2016



1. Data quality and completeness

Example:

Nebraska is
low concern
in 2017



1. Data quality and completeness

In our data, we had 25% missingness. State restriction would have us at less than 50%. After multiple imputation use zip code and other factors had it down to $< 5\%$

2. State differences

- Many concerns are the same discussed in #1.
- However, state differences are a major strength for IDD policy.

2. State differences

There have been really good methods
advancements recently, especially in HCBS

Health Services and Outcomes Research Methodology (2025) 25:29–41
<https://doi.org/10.1007/s10742-024-00325-6>



**Home- and community-based care in the new generation of
Medicaid administrative data**

Siii Wana^{1,2} · Minavu Oi¹ · R. Tamara Konetzka¹

2. State differences



Contents lists available at [ScienceDirect](https://www.sciencedirect.com)

Disability and Health Journal

journal homepage: www.disabilityandhealthjnl.com

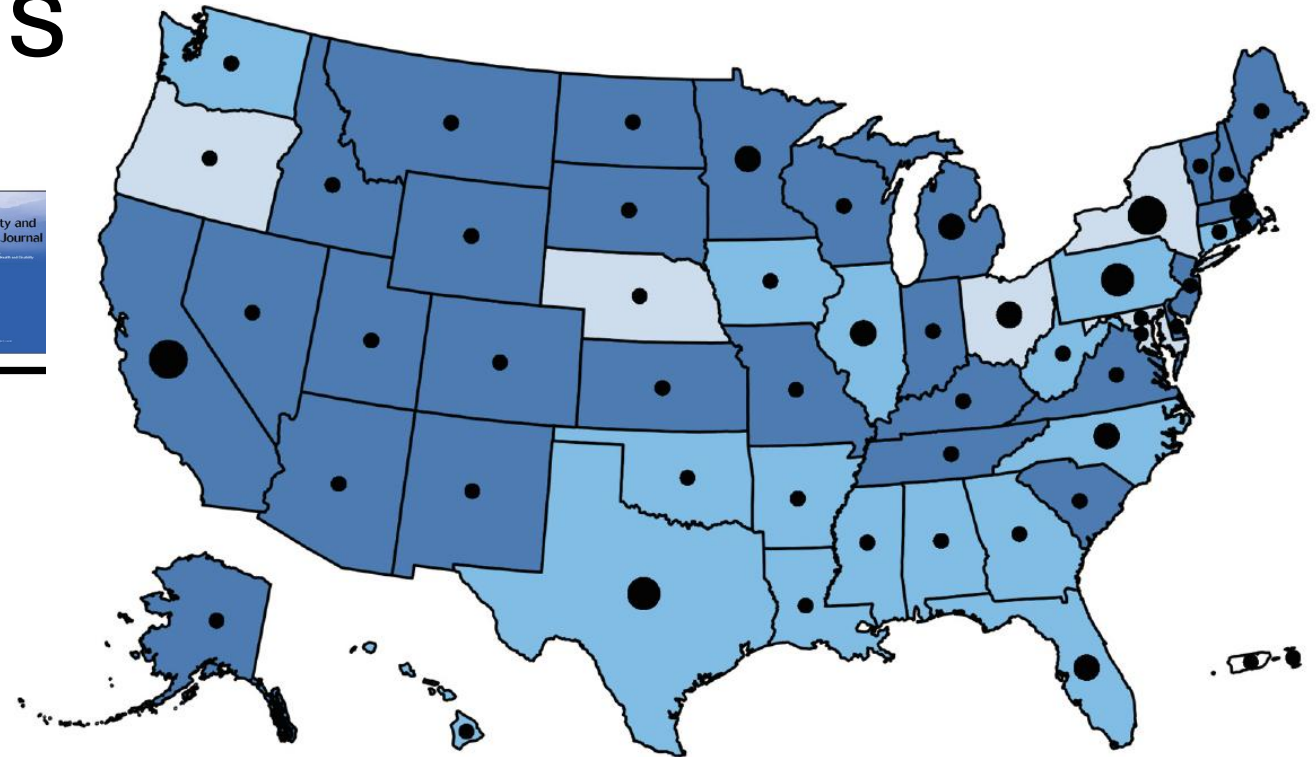


Medicaid home and community based services are vital for adults with intellectual and developmental disabilities: A descriptive study of service use among all adult enrollees, 2022

Samuel Rosenberg^a, Josue Antonio Garcia Estrada^a, Salina Tewolde^a, Alianna Higgins^a, Junjun Tao^b, A. Alex Levine^c, Emily Q. Sisson^b, Amy Michals^b, Eric Rubenstein^{a,*}

^a Department of Epidemiology, Boston University School of Public Health, United States

^b Department of Health Policy Law and Management, Boston University School of Public Health, United States



Our paper looked at coverage by state

IDD Population ● ≤ 39,999 ● 40,000-79,999 ● 80,000-119,999 ● ≥ 120,000

HCBS Coverage □ 0.00%-24.9% □ 25.0%-49.9% □ 50.0%-74.9% □ 75.0%-100.0%

use by state and count of adults with intellectual and developmental disability enrolled in Medicaid, 2022

2. State differences

Caveat: Often the straightforward approach will not work because of quality issues: adaptation is necessary. For HCBS, need to combine multiple ways of identifying use to get full coverage

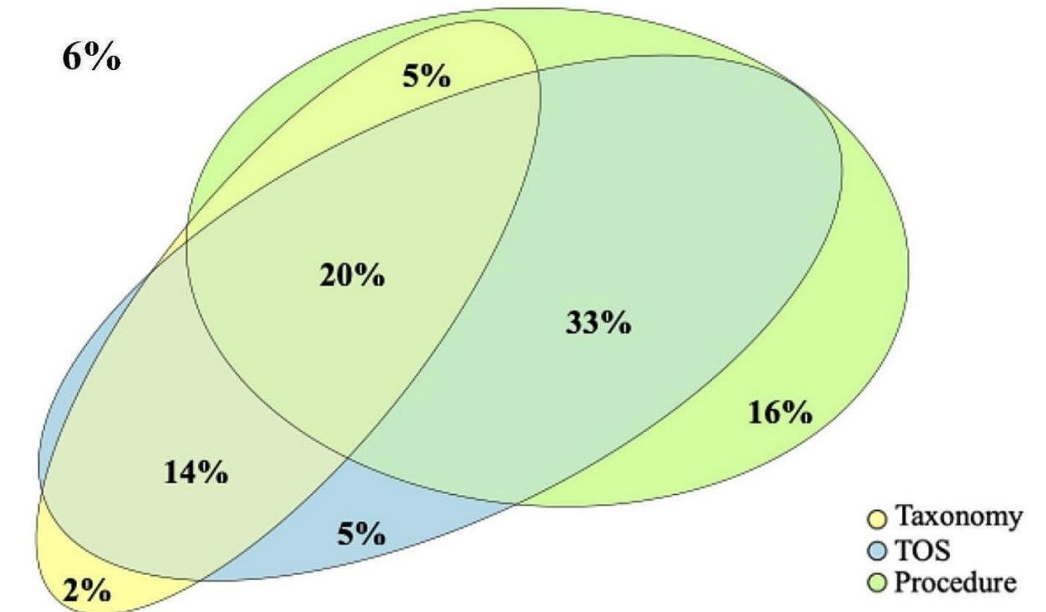
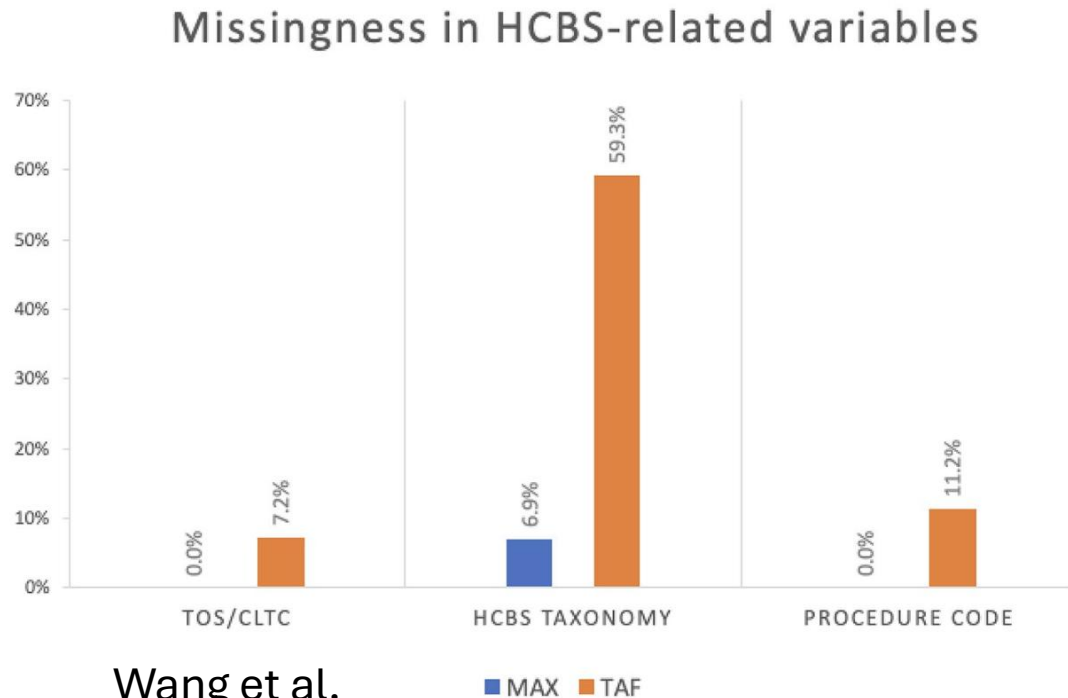


Fig. 2 Percent of 1915(c) claims/encounter records that can be identified as HCBS with TAF data by different approaches. Note: Data source: 2016, 2017, and 2018 TAF data combined
HCBS – home and community-based services.

The area in the Venn Diagram is proportional to the numbers falling into each category, except for the 6% of claims/encounter records that cannot be identified by any of these three approaches.

3. Enrollment eligibility and complexity

- Churn is not as big of an issue

 [GENE THERAPY](#) [PATIENTS](#) [CANCER](#)

Registration for the 2026 STAT Summit is open: secure your pass early and save. [→](#)

NEWS

STAT10 YEARS A decade of reporting from the frontiers of health and medicine

[Biotech](#) [Pharma](#) [Public Health](#) [Health Tech](#) [Policy](#) [Science](#)

OPINION  [FIRST OPINION](#)

How churn threatens Americans' health

Plan-hopping makes insurance companies underinvest in keeping Americans healthy

[Get Alerts](#) [Email](#) [Share](#)

3. Enrollment eligibility and complexity

Table 1. Demographic Characteristics for Adult Medicaid Enrollees With Down Syndrome or Intellectual Disability and a Sample of Medicaid Enrollees Without Developmental Disability, 2011-2019

Characteristic	Adult enrollees, No. (%)		
	Down syndrome (n = 123 024)	Intellectual disability (n = 1 182 246)	No developmental disability (n = 3 176 371)
Total person-years	820 273	8 051 162	12 384 921
Median (IQR)	8.0 (5.0-9.0)	8.0 (5.0-9.0)	3.0 (2.0-6.0)
Mean (SD)	6.6 (2.6)	6.6 (2.6)	3.3 (2.6)
Categorized age, person-years			

While employment inequity exists, Medicaid will capture IDD well

Summary

TMSIS Data have limitations but many of the more publicized limitations are of less concern for IDD because of:

- lack of churn
- high policy relevance
- Need for population research

The key is to ask the right questions for the strengths and limitations of the data



Unlocking the Potential to Identify Individuals with I/DD Using Administrative Data

Leanne Candura, MPH

Monday, September 21, 2026

Washington, DC

Agenda

- ❖ Overview of APCD & Hospital Encounter Data
- ❖ Example Study
- ❖ Recommendations

Overview of APCD & Hospital Encounter Data



All Payer Claims Database (APCD)

- Large state databases of health care claims for Medicaid, Medicare, and Private Insurance.
- More than 20 states have APCDs and allow researchers access to data.
- No single national APCD—state-by-state



Hospital Encounter Data (HED)

- State datasets on encounters (visits) to hospitals.
- States vary in who can get access to the data.
- HED are usually through state agencies, but some through hospital associations.
- States contribute their data to the Healthcare Cost and Utilization Project (HCUP).

Example Study: Maine Health Data Organization (MHDO) Administrative Data

Study Objective in Maine

- Identify people with IDD by linking APCD and HED.
- See characteristics of people with IDD in Maine.
- Compare utilization of services for people with and without IDD.

Whom and What We Studied in Maine

Population:

- Maine residents.
-

APCD Coverage:

- 100% of Medicaid and Medicare and about 70% of private insurance.
 - Eligibility, medical, pharmacy, and dental claims.
-

Hospital Encounter Coverage:

- All insured and uninsured: about 60% of Maine's population.
- Inpatient and outpatient records from hospitals, hospital-owned specialty groups, and primary care practices.

Study Design in Maine

1. Pulled together the data from APCD and HED for 2018-2022.
2. Created an identification code for all people.
3. Identified people with IDD from diagnoses.
4. Identified people with IDD if they have claim or encounter with an IDD code.
5. Created subgroups for ID, autism, pervasive DD, learning disabilities.
6. Created payer indicators for each person to capture all insurance types.

IDD Status and Types

- We used diagnosis codes.
- 59,708 people identified based on the merged data.
 - 46.1%: Autism, pervasive DD, Asperger's, (27,531)
 - 42.9%: Learning disability (with or without another DD), (25,603)
 - 23.4%: ID (with or without another DD) (13,987)

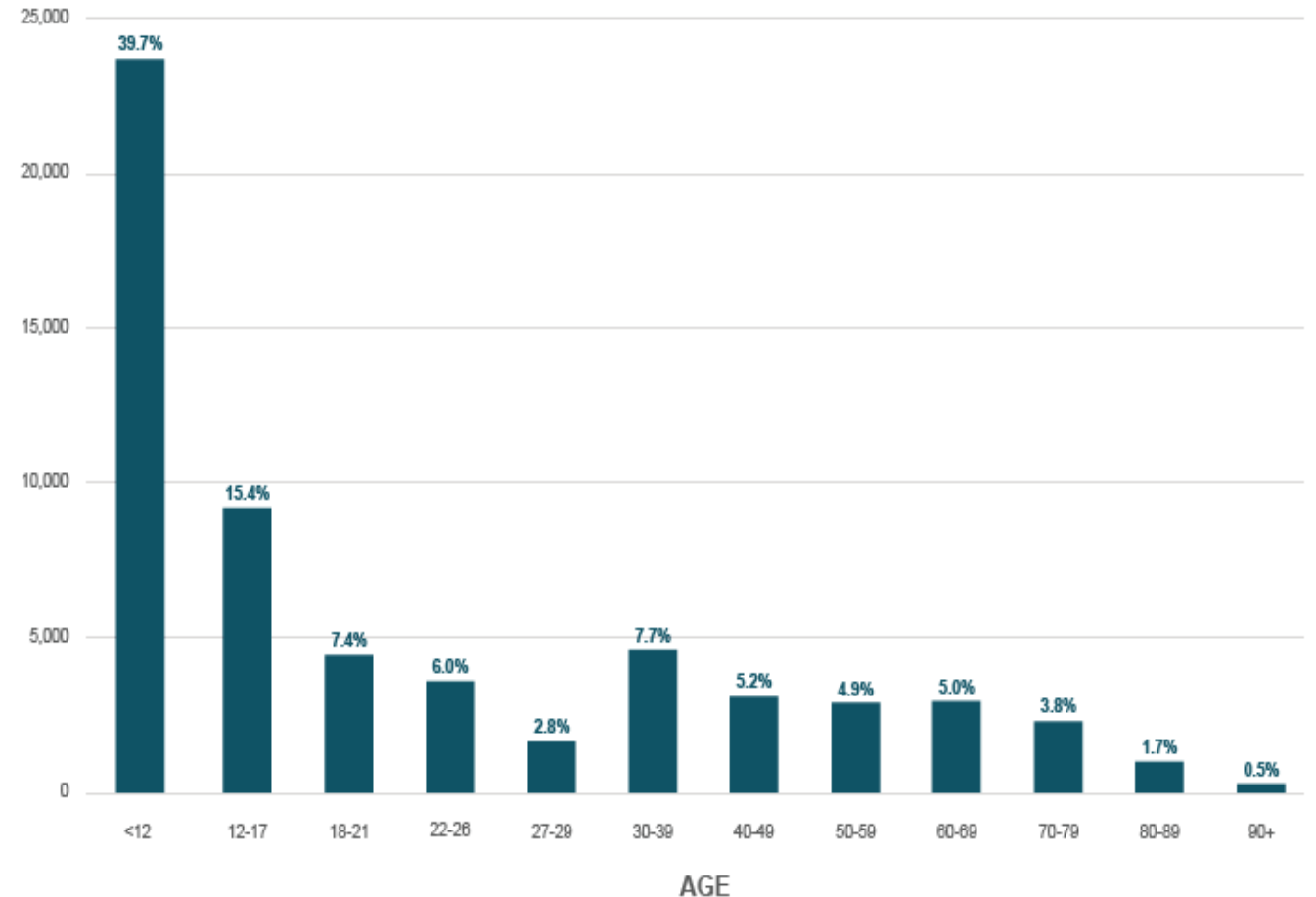
Top 10 Diagnoses for IDD

Diagnosis	Percent of Individuals
1. Autism	25.3%
2. Mixed Language	11.6%
3. Speech sounds	11.4%
4. Mild ID	11.3%
5. Other psychological development	9.0%
6. Specific DD motor	6.6%
7. Unspecified ID	6.1%
8. Expressive Language	6.1%
9. Moderate ID	6.1%
10. Other speech/language DD	3.4%

Demographic Differences

- More males (59.8% with IDD vs 48.2% overall)
- More children and young adults
- 63% were with Medicaid for all years (37,641)
- Of those with Medicaid, 19.7% were also on Medicare (7,429)

Individuals with IDD Diagnosis by Age



Study Limitations

- IDD was identified only by diagnosis codes.
- Only includes individuals who used health care during 2018-2022 (likely an undercount).
- In the future: Look for more people with IDD by using IDD service codes or list of people with home- and community-based services.

Conclusions

1. We need to identify people with IDD to see and address health inequities.
2. We can identify people with IDD population by using existing administrative data.
3. The data can show things about people with IDD, like:
 - Other diagnoses.
 - Patterns in what services are used.
 - Cost of services.
4. The example of the Maine study can help prioritize work there and in other states.
5. In the future: We could link with disease registries and vital statistics to get an even better picture.

Study Authors & Acknowledgements

HSRI

- Leanne Candura, Kristin Battis, and Alexandra Bonardi
- HSRI is a nonprofit institute providing research, evaluation, and data services to help create sustainable, person-driven systems.

MHDO

- Karynlee Harrington
- MHDO is an independent state agency in Maine that collects health care data and makes it broadly available while protecting individual privacy.

Recommendations

5 Recommendations

1. Use a standard IDD case definition so findings can be compared across states and over time.
2. Look beyond diagnosis codes to find more people with IDD.
3. Invest in person-level linkage infrastructure.
4. Compare utilization, chronic conditions, and cost for people with and without IDD.
5. Report findings back to state agencies and the IDD community.

Thank you!

Leanne Candura, MPH
HSRI Vice President
Director, Population Health
lcandura@hsri.org